

**Seattle-Everett Town Hall meeting  
Shoreline Community College  
June 6, 2002**

About 60 people attended the Town Hall meeting on Seattle's north side. Key themes at the meeting mirrored some of the earlier discussions:

- **Mental health and drugs:** A number of people expressed fear that the drug co-pays might interfere with people obtaining effective medication for mental health problems. MAA Assistant Secretary Doug Porter explained that the waiver would exempt this type of drug – as does the Therapeutic Consultation Service – on grounds that prescribers need flexibility to prescribe different amounts and brands of these drugs, which do not have the same therapeutic equivalents as some drugs in other classes.
- **Medicaid as an entitlement:** Some participants denounced what they perceive as an effort to change the entitlement nature of Medicaid rather than modeling on programs like the state's Basic Health plan, which has always used co-pays and cost-sharing premiums, as well as a more limited set of benefits. (Unlike the Basic Health program, however, the premiums discussed as part of the waiver proposal would not apply to any Medicaid recipients under the Federal Poverty Level. All Basic Health subscribers pay a premium unless the premium is paid for them by a sponsoring organization.)
- **Loss of federal funds:** Opponents of the waiver raised a point in Shoreline that has not gotten as much discussion at other meetings: Because Medicaid is a state-federal program supported by about 50 percent federal funds and 50 percent state funds, a decision not to spend state dollars would mean a "loss" of the federal matching funds.
- **Alternative medicine:** Several people at the meeting spoke forcefully about the need to broaden Medicaid clients' ability to access alternative kinds of health care – such as naturopathy, acupuncture, or other treatments outside allopathic medicine. Several people said they were able to dramatically cut their own out-of-pocket cost of health care by supporting alternative medicine.
- **Institutional care:** Relatives of profoundly disabled children in state institutions acknowledged that the amended waiver would likely not impact their family member's care, but they suggested that the state needs to reclassify ICF/MR services as a mandatory part of Medicaid so that they would never be threatened again by future funding cuts.

**Written testimony:** "Mad as hell about the waiver and I'm not going to take it anymore"

**Written testimony:** Protect institutionalized patients and make ICF/MR services mandatory

**Written testimony:** Kent Mayor Jim White opposes waiver proposals

**Other comment:**

► "Can you tell me, what exactly are 'optional children'?"

► "How are hospital co-pays supposed to work? Who is supposed to collect that or to determine when a visit is non-emergency?"

► "Here's what's wrong with your example of how the enrollment freeze would work. And that's what really happens, because the Legislature comes up with the money now automatically because it's an entitlement program. That's how Medicaid works. They came up with the money, not with the reductions you're talking about."

► “You’re changing the fundamental nature of the Medicaid program.”

► “About the unspent SCHIP funds, why aren’t they being spent to insure children? Designated funds can’t be used for anything other than what they’re intended for. That’s what they’re for and that’s how they should have been spent.”

► “Name-brand prescriptions: I’ve been going through hell for the last few months because the state has been changing my prescriptions...I was sick as a dog, flat on my back....Finally, the state let me go back onto the medication that didn’t produce the reaction...What can I not take anymore? What can I take as a generic?...My doctor and I reviewed every one of my medications, and we dropped the total from 21 down to 17....I did find one generic that I could take, but they changed my other medication without telling me...I didn’t know until I got home from the pharmacist...that was very dangerous, and it was playing with my life....It was very unfair.”

► “I appreciate your position of having to juggle a real limited amount of money, but once that’s done who is going to see these patients? Reimbursement is so low now, 40 percent on the dollar -- all of this can be negotiated and nobody will be available to see them.....The reimbursement for an average Medicaid visit would purchase a normal-size pizza.”

► “I have a child who gets \$400 a month for nursing. She has a nurse go to school with her...When we don’t have nursing shifts, my husband and I sleep in shifts...We both work so that we can have a house...I don’t understand how this will affect us...What’s going to happen to the cuts? Are we going to lose nursing, the medical equipment? We need this. We have to have it.”

► “I agree with the woman who spoke about the reimbursement rate...because there is a problem with home care nursing. Nurses go to hospitals because the reimbursement rate is so low in home care...What’s going to happen when there are no more nurses?”

► “I’m a social worker...so all I see all day long are people with disabilities. I think one of the things we must do is reiterate WHY we have this program...and that’s because it’s for the disabled, poor, elderly, who don’t have any insurance or any way to get medical care. Over the years, I’ve seen this evolve into something that no longer has that basis...I have people now who live on this money, and the reason they’re doing this is because trauma has come into their lives....(Medicaid) should be for people who simply don’t have coverage....and once we have that, we need to have some way to handle the administration of denial...Even people who have been covered for years are going through this dance to get medical care, and then, of course, we have the provider reimbursement problem.”

► “The disabled, poor and elderly...we should indeed use generic drugs when they’re available...I think we would cover who would be covered under the waiver if we get back to the basics of who should be covered in the first place.”

► “SSI -- it takes too long for the federal government to react...I have people waiting up to three years for Social Security and they still can’t work and they can’t pay for their home....This program was set up years ago for medical care for people who didn’t have any other way to get medical care.”

► “I work for DSHS and the Indian health board...I have been able to find alternative sources and treatment for my illnesses, which are taken care of at this point in time...I also ask the legal bodies

if they have considered this....With alternative medicine, my medical expenses went down from more than \$1,000 a month to \$50 a month.”

► “Medicaid itself is a safety net, and I’m really offended at the way that you made it sound as if we are so much above the Federal Poverty Level...That’s not it! Who chooses who is optional, who is the actor in that? A very good girlfriend of mine was optional – she had cancer , leukemia...Her sister was a perfect donor for a kidney, but she was kicked out of the hospital because Medicaid would not perform the operation...I myself am a health care worker...I remember working as a state employee and only having to pay \$34 a month for my children’s health coverage....my co-pays were only \$5 – Medicaid clients can’t be paying \$7 co-pays when they only get \$700 a month on SSI...”

► “If we’re going to do this waiver and do it above and beyond what the other states are doing, why not do what the other states are doing?...I realize that our cost numbers and enrollment have doubled....At the same time, prescription drug costs have gone up eight times...Only 30 percent of the people on welfare are making it, the rest are lying about it, frankly....”

► “I was making \$17,000 a month as a state worker, and I did not have to pay co-pays as high as the ones that you are trying to make people pay who have nothing.”

► “We have a disabled child who needs nursing care...First, here we are, we find ourselves in a financial and social crisis....We have a balloon moving through the population from the Baby Boom generation...But I remember seeing that balloon back in the 60s...We’ve had 40 years to plan, and we knew this was coming...There is no surprise here, but why wasn’t something done? Second question, if we do what you’re proposing, how long will it be before we have to do it again?”

► (Speaking through interpreter) “I am very unhappy...worried about who fixes ...my chair....and how he’s going to get that paid for...I work for DSHS...and am very worried...Jeff helps people in his job, but who is going to fix his chair?...Everybody wants to know who is going to take care of people if this waiver goes thru....Jeff has his own home ....and his own family...I have an aide, and who is going to pay for his personal assistant...”

► My daughter is developmentally disabled....She was diagnosed with autism when she was three ... As she gets older she has gathered mental conditions...Her medications now run between \$600-\$700 a month...Periodically she has to be put on new ones...she receives Medicaid through a CAP waiver system, but she is ineligible for SSI because when she was 18 I got her in a job training program...so if her Medicaid funding is cut off, she loses all of her health care...I’m working half-time and I don’t dare apply for Social Security when I’m 62 because I’ll have to lie, check off that I don’t have a disabled family member...”

► “I don’t care about transportation and I don’t care about education...But people need medical care.”

► “The term ‘optional,’ unfortunately, makes some people believe that they are much better off than they really are. But they really are low-income and needy.. Second, we charge...and we are unable to collect...so even if they can pay, the question is, what is the hospital going to do?...Lastly, I think you acknowledged, one of the reasons that people go to the hospital because

there isn't any other place for them to go....Until they have a place to go, the hospital is where they are going to go...and we shouldn't punish them because they have no place to go."

► "We're dropping people every month who aren't able to pay. There's a big turnaround in Basic Health all the time..."

► "I think we're sort of missing the point when we engage in that dialogue, and we're missing what happens to people of very low income who only have enough money to pay the rent and their food.... My question is what would happen to children in those families ....if their families couldn't pay the premium?"

► "I think that everybody in the room can appreciate what it is to live within a budget, but there's a crucial part of the equation that you've left out. We're talking about Medicaid...What that tells me is that you have tried to do a balancing act....adverse budget outcomes against people dying....and that the cost savings that you want to achieve through this waiver is worth the cost of people dying....My point is, what we're not getting is, what are the health outcomes? We're talking about a health care program -- yes, we need to save money, but what are the effects of that? I don't feel we're getting much information from MAA about this."

► "There is very good data that shows clearly that money spent on children's preventive health pays off in fewer health-care problems....In other words, this very cheap health care at young ages has meant better health outcomes..."

► "If we would take the state penal program, the state employees, medical assistance, the Basic Health program... Each of these organizations buys in bulk..and if they combine they would have more bargaining power....Second, allopathic-type treatment....I know that I was going to a chiropractor who saved my life...by referring me to the right people, and yet I was told that I couldn't go to him anymore because he wasn't covered....I've been diagnosed with acute depression...so consequently, I am in a very lousy situation...I'm on Social Security disability....I've cut back on my meds...I just got a new one -- one silly little bottle about this big. It started out at \$20, went up to \$40 and I was just told it's going up to \$60."

► "I'm a retired cooperative manager...I want you to know I've been working for health care as a human right for more than 60 years, so don't give up.... I don't know how many of you remember the movie, "Network"... when Peter Finch leaned out an open window and shouted, 'I'm mad as hell and I'm not going to take it anymore,' and then at his urging, viewers all across the nation leaned out their window and joined him....I'm also mad as hell when I read about these Medicaid waiver proposals and hope you will feel the same..."

► "One in six of our state's nearly six million population are poor and they suffer the humiliation and despair of poverty...in this wealthiest society in the world....Billionaires and thousands of millionaires live in this region, and yet the Department of Social and Health Services has suggested the state stick this army of poor folk with co-payments, premiums and even limiting additional medical care access. If the employment and recession continue to mount, is the state going to demand more money back from the poor who are already not getting all the services they need?"

► "This state leads the nation in regressive taxation... since 1994 our Legislature has granted more than 100 tax breaks...with a total revenue loss of \$3.3 billion. ... Then we've got to look beyond the state....at the vast military industrial sinkhole...End this gross corporate welfare! Take the

money back and properly fund health care and education for all ...and create nonmilitary jobs with living wages... We stand alone in not providing health care for all of our residents.... I'm reminded of World War II with 16 million of us in uniform and we had health care for all the years of our military service. If we can do it in war, why can't we do it in peacetime? .... We must not compound the suffering of our poor with fees they cannot afford."

► "I am now working because of the Medicaid personal care program...I have an attendant...and I work ....so I'm a taxpayer. So when you think about eliminating programs, please remember that we need state support ...so that we can stay taxpayers.....I'll give you another example...I was in a nursing home from 19 to 31 years of age...I will now be back there without my Medicaid personal care, because I would not be able to work...I think we need to take a look at what programs are the most cost-effective. If you take away Medicaid personal care, the only choice a lot of us will have will be the ICF/MR...It costs the taxpayers a lot more money for care in those institutions, and people in those institutions are not allowed to work...I know you have a tough road ahead of you, but please think about cost-effective programs....and people like me."

► "I am a medical social worker who's worked in home health and hospice...and I'm very concerned about people who need personal attendants to stay in their own homes rather than nursing homes, which are much more expensive.... I also have a problem with our governor...with a lot of years with lobbying and advocacy, the Legislature just this session passed a wage increase for these home health care workers...now they make \$7.68 an hour...and they have no health care benefits... which means they might be part of these people locked out of Medicaid... So in order to keep these health care workers in homes where people really depend on them...the Legislature finally passed this, and then the governor vetoed it...what if DSHS goes through with this waiver, and what if next year the Legislature actually increases the budget for DSHS, what's going to stop the governor from vetoing that, too?"

► "Second, after what you heard throughout the state here, is this going to change your response to our congressional legislators who are opposed to this waiver? And will you change your proposal based on what you are hearing?"

► "These are incredibly hard choices that you're making, and it's hard to sit through the discussion...one of the things that happens when kids are uninsured is that they don't get preventive care...They will be seen in the hospitals, but they won't be going in for an annual checkup... The hospital co-payment on the emergency room will also...put the pressure on the person using the services, and you've said that you're going to find a way to make it work, and I'm really skeptical that there is a way to make it work...I don't see how this co-payment is going to accomplish what you intend."

► "There should be payment for the alternative (medicine) treatment because it is cheaper, and it is more effective...I am wondering about a possible individual medical plan...If I can't have kids, why is there money in there covering me for maternity benefits? Why can't you design an individual plan? Would it be too much administrative problems?"

► "For at least 10 years, we in the disability community have been trying to show...it costs less to treat people in the community than in an institution...In fact there's a court case...the Olmstead case, yes...and in Congress there is a bill that would ask that one-quarter of Medicaid funding originally slated for nursing homes and other institutions go for community care, care in your own apartment or home..."

► “At Harborview....I also had the first epileptic seizure I’ve had in 16 years....four or five days of confusion....and for the fourth time in my life I was involuntarily committed on a psych ward....i was in there seven days on a 72-day hold, and I was told this was common...I got out, they had injured my shoulder and my elbow...I told them I was epileptic...I had to go three different times to Swedish to get my arm fixed up....and this was not unusual...If you have enough money, over \$10,000 to do this to me, why do you have to take money away from them?”

► “If you freeze people out of Medicaid and they are forced to go to the emergency room and then that is more expensive for the state. Won’t it mean more money and coverage for those people? We already have a problem with access, and it seems like this would increase the problem of access.”

► “The cost gets spread out to everybody, and then other insurance premiums go up. And then you just compound the problem.”

► “I just wanted to bring up the aging and disability population, because these populations are growing...people are living longer and getting older...When you look at the medical assistance budget, you can put the growing enrollments together...But when I look at the optional service list, these are services that are used by people who are disabled and elderly...These are things that people need...When you look at the big picture, these costs will be absorbed elsewhere....People will no longer be able to live in the community and they will be forced into nursing homes...There is a larger discussion about this that needs to take place.”

► “I am the political director of Service Employees International Union (SEIU) ... representing thousands of hospital and health care workers... We oppose the waiver... We’re worried about access and eligibility...A lot of things that we’re working on have been addressed...We’re interested in solutions to the health care crisis by making these changes that actually save money...It’s hard for me to look at this plan and see where it really saves money...It just shifts costs elsewhere, hospitals will have to absorb much of it...If you cut people off from other care, they will just go to the hospital.”

► “I’m a parent and we have a 7-year-old son with Down Syndrome...Early on we got on the CAP program, and I’m grateful...My son couldn’t eat normally for three years... I’m happy to say that we’re extremely grateful that our needs were met...We were stretched to the limit....So things are going very well for us now, but it could change....and I’m just here to speak for people in similar positions...where they greatly appreciate the Medicaid coupons...I just want to voice ...I’m very worried about being optional and losing that medical coupon under the CAP program.... It’s one small piece of the pie, but are people talking about things like an income tax? I’m all for sliding scales...I also wonder if you’re looking at DD case managers and talking to them about these changes and what would happen under them.”

► “I’m going to be very brief, because I want you to get home...nothing personal, you understand...I’m not a health care worker...I’m a parent of a profoundly retarded child who is cared for at the Fircrest School, which is nearby. I want to commend the waiver team...for getting the issues out and listening to the concerns. My message is quite simple: I’m asking you as the parent of a child to remove the ICF/MR services from the optional services list and to leave it alone...It’s going to put a roadblock in terms of future needs for children to be admitted....So please remove the ICF/MR. It doesn’t impact anything at the moment, but it may in the future.”

► “I represent Columbia Legal Services and my entire practice is to represent people with disabilities... I’m very concerned about the lack of specificity...The federal government said the first proposal was too general, and yet this proposal is still vague...Will you submit a detailed proposal, as the federal government requested, and will those details include who you are proposing would have a benefit change or an enrollment freeze? ... Because those details aren’t out in the open, we can’t have the same public debate we could if they were on the table... In the past, when cuts were threatened, because it was public and in a specific and public fashion....citizens got out and told the Legislature and the Governor ... not to cut the program, and it worked....The waiver would change the process and let some of those people make their decisions behind closed doors, and we wouldn’t have the same opportunity to speak out publicly....It’s deeply alarming to me that the Medicaid agency would put forward a proposal that would make the program so vulnerable to this.”